

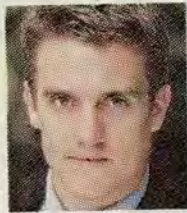
AS A NURSE and health visitor with 25 years' experience, Carole Jones thought she knew the workings of the NHS inside out. But when her 85-year-old mother Maureen was admitted to Addenbrooke's Hospital in Cambridge last year having suffered a stroke, she was totally unprepared for what followed.

Her mother's chances of recovery having been written off by medics, a decision was taken — without Carole's knowledge — to place Maureen on the controversial Liverpool Care Pathway (LCP).

This is a plan ostensibly designed to ease the suffering of the dying, which can involve the heavy sedation of a patient and the removal of tubes providing food and fluid.

Over the past week, families have contacted the Daily Mail saying they believe their loved ones were wrongly put on the LCP by hospitals when they were not in fact close to death, fuelling the suspicion that it is used to hasten deaths to save the NHS money and free up beds.

This year, Professor Patrick Pulicino, a consultant neurologist for East Kent Hospitals, and Professor of Clinical Neurosciences at Kent



by Tom Rawstorne

University, told a conference the LCP had become an 'assisted death pathway'.

'Very likely, many elderly patients who could live substantially longer are being killed by the LCP,' he said.

It is a view with which Mrs Jones, 64, has some sympathy. It took Maureen, a widowed mother of two from Haverhill in Suffolk, 12 days to die after her admission, during which time she was deprived of food and water.

Carole was by her mother's bedside, recording in a deeply moving journal her observations, not just as a loving daughter, but also as a healthcare professional.

Here, the Mail reproduces an edited version of that journal — which raises further disturbing questions not just about the Care Pathway, but more generally about the dignity offered to the dying in NHS hospitals.

MONDAY, JULY 25, 2011

I RECEIVE a call from Denise, a carer at The Meadows, the home where Mum has been looked after for the past year. I can tell from her tone that something is seriously wrong. She tells me that Mum, who while showing early signs of dementia had been in relatively good health, has had a stroke and been taken to Addenbrooke's Hospital.

My husband Peter and I immediately jump in the car, but it takes four hours from our home in Chepstow. When we arrive, my mother looks so poorly, so helpless: her mouth distorted, her lips pouting. My heart goes out to her. How cruel can nature be? When we have to leave her at midnight, I hate it. I want to be with her, to let her know she is not alone. But in hospital that's not an option.

TUESDAY, JULY 26

VISITING hours are only 3pm to 5pm, and 7pm to 8pm. Mum looks so ill. She is awake. I talk to her and hold her hand. I say it is Carole and I'm sure she replies: 'What now?'

I just want to comfort her. I know she will be feeling frightened as she hated being in different places, especially alone. An occupational therapist asks us all about Mum's mobility status, whether she could walk using a frame. We say she was quite limited, and had been deteriorating over the past few months.

The doctor, a senior registrar in his last year of training, then says he can see us, and we are led to the 'quiet room'. He explains that Mum has suffered a massive right-side stroke, and that given her dementia and very limited mobility, the best treatment would be palliative care. There was nothing that could be done for her.

They will not be giving intravenous fluids in case they lead to a chest infection, and there will be no quality of life for Mum [if she carries on].

Not nice to hear at all, yet I do realise that Mum is very ill. The doctor says that without fluids, the end will come within three to four days at the most.

When I come away from talking to him I am in a state of shock. I know Mum's had a big stroke, but they are pretty much writing her off. When I come out of that meeting, I don't expect her to last the week.

WEDNESDAY, JULY 27

THERE is confusion about whether Mum might be moved out of the hospital and back to The Meadows. I am amazed at this. How could she be moved if she is so poorly? In the end, nothing comes of it.

THURSDAY, JULY 28

I PHONE the ward in the morning and am told Mum is comfortable, and pointedly reminded that visiting hours are 3pm to 5pm.

I find this insensitive and unnecessary given that I had been told on Tuesday that Mum was receiving palliative care. It makes me feel so useless, and that I ought to fight to see her. How can I reassure her if I am not there?

FRIDAY, JULY 29

WE ARE back on the ward again at 9.30am asking to see her. I am not sure if this is very popular with the nurses, but I want to be with Mum. After all, we had been told the end could be any time.

I have always been led to believe that when this point is reached, nothing can be done other than keep the patient comfortable: care of the dying, basically. As a healthcare professional, it is a hard to take when the 'patient' is your own mother.

SATURDAY, JULY 30

THE nurses have agreed I can see Mum at any time, so I'm on the ward by about 10am. Mum seems about the same really, sleeping a lot but when awake, muttering or trying to say something, over and over again. I just keep telling her that Carole is here, and that I am holding her hand. I hope she can understand that. I just don't know whether she is in pain, or just frustrated at not being understood.

A female junior doctor speaks to us, informing us that there had been a discussion the day before and it had been decided to commence the Liverpool Care Pathway (LCP) for Mum. I have not heard of the LCP, so the doctor explains it is a plan of care put in place for the dying. Why weren't the

family told of this, or included in the discussion?

The fact that Mum had dementia and limited mobility has been mentioned a few times, and now it is mentioned again. Was this the criteria used to decide that all active treatment should be withdrawn? On the second day, the doctor had said Mum would have no quality of life, but who really has the right to decide that?

A consultant comes later that day to sign the paperwork the junior doctor had commenced. It states that intravenous fluids had stopped on Wednesday night. He briefly explains what we had already been told: [there is] no active treatment, and most people cannot go longer than about three to four days without fluids.

It sounds so barbaric.

That afternoon, we are moved to the side ward. Now Mum is there, does this mean she will soon die?

SUNDAY, JULY 31

THE chaplain comes and talks to us for a while, and then says the 23rd Psalm for Mum, also the Lord's Prayer. It is very moving and I feel quite emotional. Mum seems to let out a big sigh. In the side ward, she is asleep nearly all the time. I think she feels the peace and quiet in there.

I am sure Mum is aware of Pete and me being there. She flickers her eyes, or sighs at times at Pete's voice. This would have been such a peaceful time for Mum to pass on.

MONDAY, AUGUST 1

LAST night, Mum had to be moved back to the main ward because there was another admission coming in and, as it was a man, he had to go in the side ward because of the policy on mixed wards.

To top this, Pete is told he can't stay with me now because Mum is on a female ward. I try to tell the nurses that I can't get through this without Pete beside me, and it's finally agreed that he can stay with me — but only if the curtain around the bed is closed at all times.

A sister looking after Mum asks if I think she would like her hair washed. I reply that she would. When we return to the ward, the sister tells me that Mum had communicated with her that Wednesdays were her hair-washing day. They were.

Now I am confused. We had been told there was no hope for Mum, therefore no treatment was being given, yet she could comprehend and communicate about her usual hair-washing day.

This is heartbreaking.

How can anyone be so sure that there is no hope for anyone? We speak to the lead doctor, the consultant of the whole team, who tells us that the severity of the stroke means there is little that can be done. It is all very depressing.

About 7pm, a nurse comes by the bed with the diamorphine pump for Mum, which delivers a pain-killing sedative. This seems a bit final, but I have to accept this. The nurse says that now Mum is on the Care Pathway, we can stay with her as long as we want.

I say that we were under the impression that Mum had been on this programme since Friday. The nurse says it is now official. I reply: 'You mean the boxes are now ticked.'

TUESDAY, AUGUST 2

ANOTHER doctor comes with the scans and explains what happened when Mum was admitted. The scans show evidence of a massive stroke and how Mum's brain had been previously damaged by dementia.

Although this provides some proof of Mum's condition, I still feel very sad about it all, and uneasy that it means she is not being treated with any fluids, because it is perceived she would have no quality of life.

I say that Mum had been without fluids since Wednesday night. The doctor had not realised this, and could not understand how Mum could go so long without fluids.

I sit with her most of Tuesday night. She moans and taps her right knee. I notice that she has a large bruise around her knee, which I assume was the cause of her moaning and discomfort.

WEDNESDAY, AUGUST 3

I EXPLAIN to the registrar about Mum's knee, how she had showed me this by tapping her leg. The registrar reviews her prescription chart and increases the diamorphine as he thinks Mum is in pain. I explain that I do not think she is in pain, but trying to communicate to be moved.

The registrar still advises the increase

SMOOTH
JUST GOT
SMOOTHER.





Written off:
Maureen
with her
daughter
Carole

My diary of Mum's awful death on the Liverpool Care Pathway

One nurse's heart-rending account of how, without telling her, doctors decided to put her mother on a controversial 'pathway to death' – and the long, agonising days that followed

in diamorphine to be the best option. I guess Mum is just not doing what is expected, and that the lack of fluid is not working in the time expected.

One member of staff even says that 'it was hot, therefore (my mother) would lose more fluids so it would not

be much longer'. I also understood that I should not even put a damp cloth to my mother's mouth in case she gleans some moisture from it, which would prolong her life. Surely health professionals must realise they are looking after human beings with

feelings, not just 'objects' to be dealt with in a textbook fashion?

THURSDAY, AUGUST 4

WE SIT with Mum and she still tries to communicate with me. I suppose some people would say I am kidding

myself. I know she is trying to say something to me, but I can't quite work out what it is.

It is the most heart-rending thing to witness my mother being so vulnerable. I just want to protect her and ensure she knows she is not

alone, that I am there with her through this final ordeal of her life.

Two nursing assistants come to turn her, despite the consultants having written in Mum's notes that she did not need such regular repositioning, that her comfort is paramount now. I stay and watch but soon wish I hadn't. A sliding mat is put under her by the nursing assistants, who are busy chatting to each other about another member of staff, so they don't notice that Mum's head is not supported so that it falls backwards when they move her on the mat.

Poor Mum, the look of terror on her face will remain with me for ever. Her eyes are wide open. How can anyone be so intimately involved with a patient, yet not notice what they are doing to them? They just have no empathy for my poor mother. I talk to her, tell her I am here, and that no one will move her again.

FRIDAY, AUGUST 5

THE early hours, and Mum's eyes remain open now, staring into mine all the time. Her breathing gradually becomes more shallow. I know she is dying, yet her pulse continues to throb. It seems her heart is just not ready to let go, yet her body cannot cope.

Is this due to lack of fluid and nourishment, I wonder? I will never know. Mum gradually seems to be struggling for breath, until she eventually takes her last gasp of air. I will never forget that, to the very last, Mum has fought what is happening to her.

LOOKING back, I have no regrets that I was by her side during the last 12 days, however harrowing it was. I wanted her to know she was not alone, and that I loved her. I only hope she knew and took some comfort from that.

I always understood my mother's prognosis. I knew she was dying and that there was little hope of rehabilitation. However, I am concerned about quite a few aspects of her treatment during those 12 days.

The dismissive attitude of some of the staff, the lack of continuity of staff looking after Mum, the ridiculous restrictions of visitors to dying relatives, the unnecessary movement to a main ward to die, and the lack of information with the Care Pathway.

The care pathway was not fully explained to me, and I am not convinced this is the best plan to follow for dying patients. It seems to be a process more for staff than patients.

Nothing will ever alleviate the stress and guilt I feel that I allowed nursing and medical staff to place my mother on the LCP without being given enough information about it.

Obviously, it takes time to come to terms with the loss of a parent, but in my case, the experience of watching my mother die in the way she did will haunt me for ever.

Were we right to agree to no active treatment? We are all humans. Would you treat your mother this way? I guess not.

■ IN REPLY to a written complaint from Mrs Jones about her mother's treatment, Addenbrooke's Hospital stated that there was 'no record that the family were not happy for your mother to be treated palliatively'. It adds that because of the patient's poor prognosis she was placed on the LCP, with the agreement of Mrs Jones, to try to keep her 'comfortable'.

It continues: 'Had there been any indication that your mother had the potential for rehabilitation, this would have been pursued.'

The letter, dated March 29 of this year and signed by the hospital's complaints manager, concludes: 'It is evident from your letter and from the responses which I have received from the staff who have looked into your concerns that we could have made you and your family's life a lot easier... helping you to cope with the sudden and catastrophic stroke which your mother suffered.'

'I am truly sorry that this was the case. Please be assured that lessons have been learned by your experience, and actions have been taken to try to prevent another family feeling as you have done.'

A spokesman for the Trust last night said they had offered to meet Mrs Jones to discuss any further concerns.